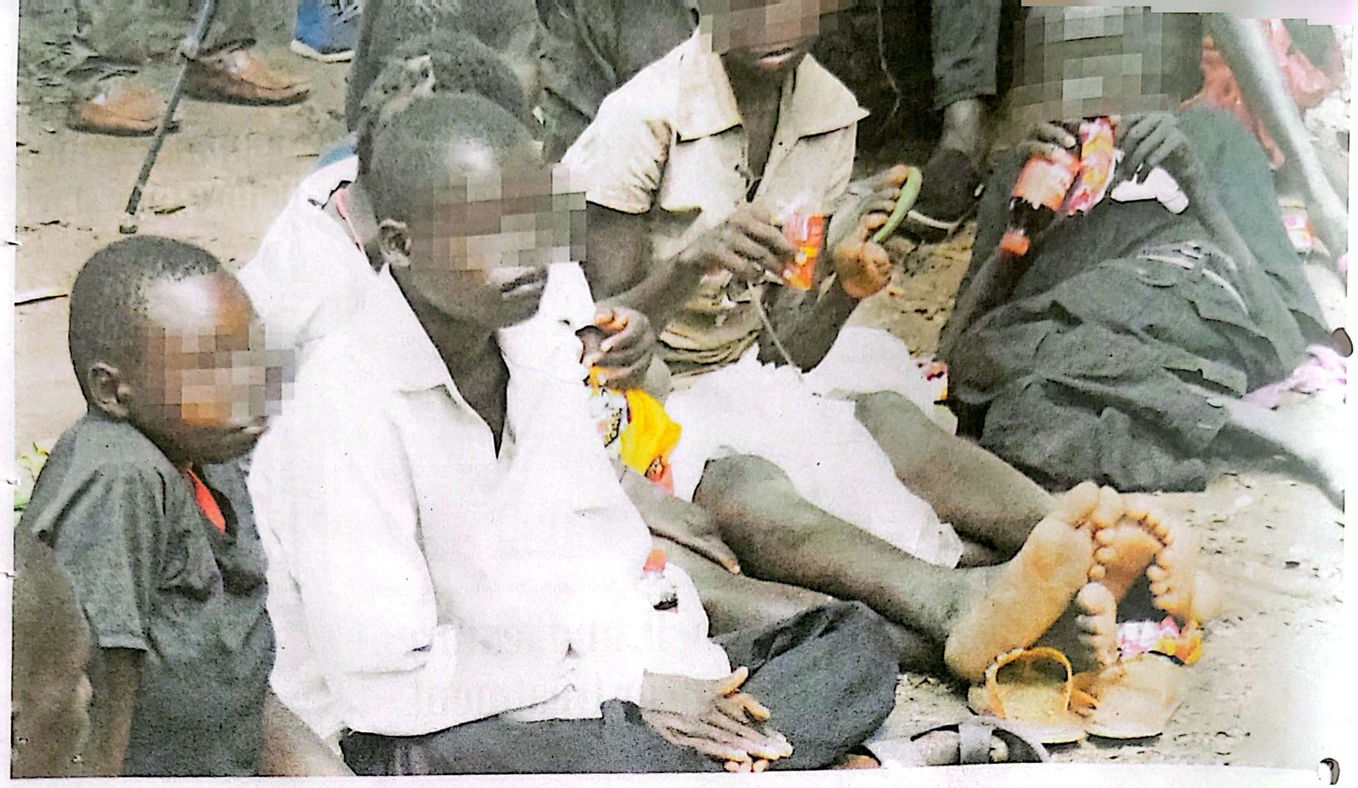

Why nodding syndrome remains a silent killer in Pader

More than two decades after the first cases were reported in northern Uganda, nodding syndrome continues to cast a long shadow over Pader District. While no new infections are being recorded, families are still losing children, often before reaching medical care, exposing gaps in access, reporting, and long-term treatment.

BY GEOFFREY OYET OKWERA

Agnes Laker faced relentless hardship in her effort to keep one of her sons alive after he was diagnosed with nodding syndrome in Pader District, Northern Uganda.

Despite her limited resources, emotional strain, and the heavy burden of caregiving, she remained determined to protect her child from the devastating neurological condition.

Laker dedicated herself to caring for her son every day. She monitored his seizures, fed him when he could no longer eat independently, and safeguarded him from injuries during his frequent nodding episodes. Her home became both a shelter and a clinic, as she managed her son's illness with little external support.

The disease not only threatened her son's life but also imposed immense psychological and financial stress on the entire family.

She recalls a heartbreaking moment when her son's condition suddenly worsened, prompting her to rush him to Angagura Health Centre III in Pader District. Despite her determination, he passed away before they could reach the facility.

Her experience reflects the painful reality many families in the community face, where caregivers often must travel long distances to access medical services. Many children continue to suffer from irreversible neurological damage, underscoring the lasting impact of nodding syndrome.

Deaths beyond health facilities

Laker's story reflects the struggles faced by families across northern Uganda who continue to deal with the long-term effects of nodding syndrome. While the large-scale outbreak of the early 2000s has been largely contained, the condition is still prevalent in affected communities.

Dr Charles Omara, a clinician at Angagura Health Centre III, confirms that some patients die within their communities before they can access medical care. He highlights that limited access to anti-epileptic medications and supportive treatments complicates the management of the disease.

"We have reached out to Gulu Regional Referral Hospital to strengthen the supply of essential medicines. Increased availability should help improve outcomes for these children," he states.

Delayed medical assistance

Information provided by Godfrey Ochaka, the executive director of Pimar Charity Foundation Uganda (PICFUG), indicates that at least four children have died from nodding syn-

By the end of the last financial year in June 2025, Pader District had recorded a total of 1,359 cases of nodding syndrome, including 562 severe cases. PHOTOS/ FILE

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From 2015 onwards, official records indicate that northern Uganda has not recorded new infections, although many children continue to live with the long-term neurological effects of the syndrome. Families in districts such as Pader still face the ongoing challenges of caregiving, managing seizures, and navigating limited access to treatment and support.

Nodding syndrome may no longer be spreading, but its imprint remains on the communities that bore the brunt of the outbreak, a reminder that the disease's impact lingers long after its peak.

In northern Uganda, retrospective studies suggest that the earliest children affected appeared between 1997 and 2000, primarily in Kitgum and nearby areas.

THE STORY OF NODDING SYNDROME IN UGANDA

Nodding syndrome is not new to East Africa. Similar head nodding illnesses were first described in Tanzania and neighbouring regions in the 1960s, long before Uganda reported its first cases. In northern Uganda, retrospective studies suggest that the earliest children affected appeared between 1997 and 2000, primarily in Kitgum and nearby areas.

During the early 2000s, cases steadily increased in Kitgum, Pader, and Lamwo districts, mostly among children aged five to 15. By 2007-2009, thousands of children were living with the condition, prompting national and international attention. Surveillance investigations in 2009 documented hundreds of cases, raising alarms about the scale of the problem.

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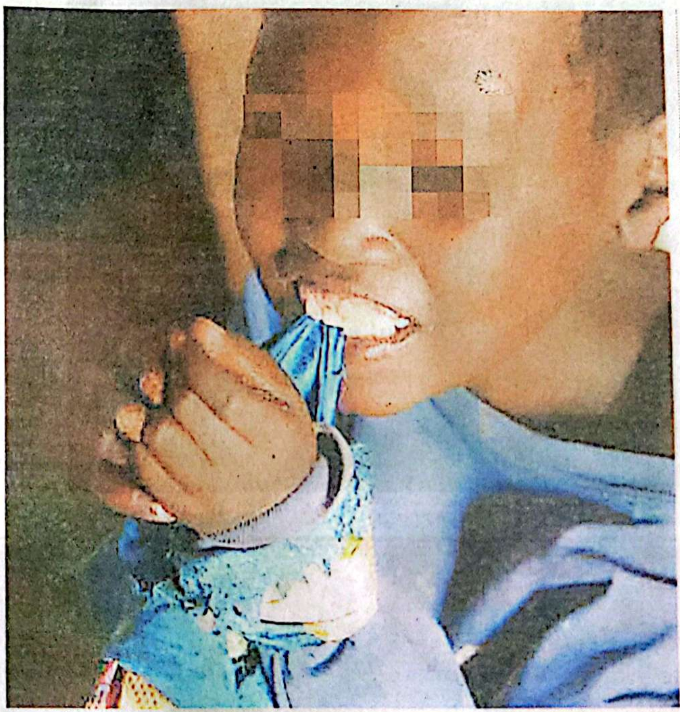

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drome-related complications in the past three weeks. Many deaths reportedly occur in the community and may go unreported at health facilities, making documentation and timely intervention challenging.

However, health officials caution against attributing all neurological deaths to nodding syndrome. Dr Samson Ocaya, the in-charge of Angagura Health Centre III, emphasises that some children exhibiting nodding-like symptoms may suffer from other serious conditions, such as malaria or other neurological illnesses.

"This child could have died if they had not been brought to the health facility in time. Unfortunately, many deaths are sometimes incorrectly attributed to nodding syndrome when treatable illnesses are the actual cause," says Dr Ocaya. He advocates for an integrated treatment approach that addresses nodding syndrome alongside other underlying health conditions.

Currently, Angagura Health Centre III sees between 75 and 130 patients daily, with numbers rising above 230 during the rainy season due to an increase in malaria cases. Health workers warn that the growing patient load is straining staff, medical supplies, and service delivery.

The drug supply question

Concerns have been raised about alleged shortages of medicines for nodding syndrome in Pader District. However, Emmanuel Ainebyona, spokesperson for the Ministry of Health, clarifies that the routine distribution of essential medicines to health facilities is ongoing nationwide. He explains that the procurement and supply of medicines are managed by the National Medical Stores (NMS), and health facilities need to coordinate with NMS to receive their stock.

Sheila Nduhukiire, principal public relations officer at NMS, confirms that medicines for nodding syndrome are available. She notes that once districts place their orders, deliveries are processed within 24 hours, with minimal logistical constraints. "This is a matter of ensuring proper coordination between districts and NMS. Once the request is made, medicines are delivered promptly," Nduhukiire stated.

Dr Benson Oyoo, the district health officer for Pader, confirms that the four recently reported deaths did not occur at public health facilities. He encourages communities to seek timely medical attention for any child displaying neurological or febrile symptoms.

By the end of the last financial year in June 2025, Pader District had recorded a total of 1,359 cases of nodding syndrome, including 562 severe cases. Although no new infections have been reported, hundreds of children continue to live with the long-term effects of the disease.

The lingering burden

Nodding syndrome impacts the nervous system in a way similar to polio, leading to irreversible neurological damage. Health workers are focused on providing long-term treatment and supportive care, utilising anti-convulsant medications such as carbamazepine to manage seizures. However, sodium valproate, another commonly used anti-seizure medication, has not been supplied by the government.

Dr Oyoo expresses optimism after recent deliveries of medications to Pader District by the National Medical Stores (NMS). "Carbamazepine has been fully supplied. I urge
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